
Accord
Achieving Comprehensive Coordination in Organ Donation

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DUTCH TRANSPLANT FOUNDATION

Sharing data internationally on living organ donation:

the experience with the ACCORD pilot

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Goal of the ACCORD pilot

- Are the WP4 recommendations workable?
  - Data fields and definitions
  - Technical recommendations

ACCORD WP4 pilot

- Data fields and definitions
  - Kidney donors only
  - Inclusion of all donors who donated their kidney in 2010 and 2011
  - Follow-up was 1 year
  - All items from Accord kidney dataset
  - No mandatory fields

ACCORD WP4 pilot

- Technical recommendations
  - A web based database with
    - Direct key entry
    - File upload entry
    - Download facility
  - Approachable by common internet surfing programs
  - Official language is English

ACCORD WP4 pilot

- Cooperation with Hospital Clinic of Barcelona
  - Frequent contact without any delay
  - Weekly reports to monitor progress
  - Problems and questions were solved immediately

Evaluation of the pilot

- Practical and technical evaluation
- Data evaluation

Evaluation of the pilot

- *Practical and technical evaluation*

- Data evaluation

Evaluation of the pilot

Key entry (5)

- Croatia
- Latvia
- Lithuania
- Portugal
- Slovakia

File upload (4)

- The Netherlands
- Poland
- Spain
- United Kingdom

Practical and technical evaluation

- A questionnaire was developed
  - Positive findings
    - The ACCORD WP4 pilot registry is a suitable way to collect living donor follow-up information.
    - Direct data entry and file upload are both good possibilities to enter data
    - The data download functionality worked well

Practical and technical evaluation

- A questionnaire was developed
  - Problems
    - The size of the upload file was limited due to a technical setting in the application.
    - In the download file decimal separator differed
    - The countries participating in the file upload encountered some problems
      - Not all ACCORD items were available
      - When the ACCORD items were available the definitions were often completely different
      - Translation of the items was very time consuming
    - A lot of missing values were encountered in the original medical files (both in key entry and file upload).

Evaluation of the pilot

- Practical and technical evaluation

- *Data evaluation*

Data evaluation

Country	Number of donors	Percentage of the total included donors	% of expected
Spain	343	11.8	62.1
United Kingdom	2049	70.4	99.8
Croatia	15	0.5	51.7
Lithuania	11	0.4	100
Latvia	5	0.2	100
The Netherlands	337	11.6	36.9
Poland	90	3.1	100
Portugal	39	1.3	39.8
Slovak Republic	20	0.7	100
Total	2909		77

Evaluation of the pilot

- Structure of the ACCORD database
  - Predonation data
  - Data during donation (till discharge)
  - Follow-up (from discharge till 1 year after donation

Predonation data

Predonation data

Variable name		Lowest value	Highest value	Percentage missing values
Mean age ± sd (yr)	47.4 ± 12.0	18	82	0.1
Gender (male);%	43.4	-	-	0
Mean weight ± sd (kg)	75.4 ± 14.0	39.5	140	7.7
Mean height ± sd (cm)	168 ± 9.9	122	198	10.3
Blood group %				1.5
- A	34.3	-	-	
- AB	0.7	-	-	
- B	9.2	-	-	
- O	55.8	-	-	
Ethnicity %				26.9
- Asian	7.5	-	-	
- Black	4.4	-	-	
- Mixed	0.3	-	-	
- Oriental	0.5	-	-	
- White	86.3	-	-	
- Other	0.9	-	-	

Predonation data		Lowest value	Highest value	% missing values
Relation type				1.3
Related genetically (%)	61.4	-	-	
Related non-genetically (%)	26.9	-	-	
Unrelated (%)	11.7	-	-	
Mean creatinine (µmol/L) ± sd	74 ± 14	37	158	7.2

Data during the donation procedure (from donation till discharge)

Data during donation procedure		Lowest value	Highest value	% missing values
Mean length of hospital stay (days) ± sd	4.2 ± 2.5	1	36	20.2
Left kidney donated %	84	-	-	12.0
Operation technique		-	-	8.3
- Open (costal resection) %	0.4	-	-	
- Open (no costal resection) %	8.5	-	-	
- Open (mini incision) %	3.2	-	-	
- Laparoscopic (standard) %	45.8	-	-	
- Laparoscopic (hand assisted) %	42.0	-	-	
- Other %	0	-	-	
Complications (Y) %	10.1	-	-	9.7
- Blood loss %	0.2	-	-	
- Re-operation %	0.8	-	-	
- Infection %	1.9	-	-	
- Thrombo/embolic %	0	-	-	
- Dialysis %	0	-	-	
- Cardiac arrest %	0	-	-	
- Other %	9.0			

Follow-up data (from discharge till 1 year)

		Lowest value	Highest value	% missing values
Donor lost to follow-up %	24.0	-	-	6.1
Death within 1 year (Y) N	2	-	-	
Mean death interval after donation (months)	2.7	2.4	3.0	
Antihypertensive treatment		-	-	29.3
- **Nothing %**	92.9	-	-	
- **Diet only %**	0	-	-	
- **Medication %**	3	-	-	
- **Other medication %**	4.1	-	-	
Mean creatinine (µmol/L) ± sd	104.9 ± 21.4	46	189	29.8
Proteinuria (mg/mmol kreat) ± sd	4.1 ± 11.1	0	80	93.4
Did the donor return to previous activity level (Y) %	98.2			42.0
Mean return to previous activity (months) ± sd	2.5 ± 1.7			53.5

Age	Creatinine level before donation (µmol/l)	Creatinine level after donation (µmol/l)
18-45 years	74	102
46-60 years	74	105
61-65 years	74	109
65+ years	75	112

Conclusions of the data analysis

Results

- 2 deaths were encountered (0.07%)
  - Deaths were not related to the transplant procedure.
- No donors needed renal replacement therapy during follow-up.
- Few donors used antihypertensive drugs
- Few donors had mild proteinuria
- Few donors had adverse events
- The great majority returned to pre-donation activities within 3 months
- The length of hospital stay was rather short (4 days)

Recommendations for a living donor database

- A dataset with the same items and definitions is essential for an international registry
- Web based application with direct key entry, file upload and download facility should be maintained
- The registration of proteinuria in different units should be adapted.
- Only severe complications should be reported according to international standards

MANY THANKS TO ALL PARTICIPATING COUNTRIES

The pilot was a great success.

The living donor registry can start tomorrow